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None declared

COMMENTARY

Family duty is more important than rights

Families are ever present in health care and health research. They sit by the beds of our patients, we ask about their health when taking a medical history, and they are data points in a genetic pedigree study. Families are ubiquitous, but they remain otherwise largely invisible to physicians and researchers. All too often, family members are not

included in conversations regarding patient care. Rarely are they asked whether they wish to share health information routinely collected in histories and pedigrees.

Patients' rights to informed consent, confidentiality, and equality have transformed the relationship between physician and patient. Rights, however, describe only 1

possible relationship between moral agents. Philosopher Benjamin Freedman refers to rights as a part of the justice of strangers.¹ Rights—for example, the right not to be touched without consent—make perfect sense in the context of our daily encounters with people unknown to us. They are claims to something or against someone and, accordingly, are inherently procedural. For instance, a rights-based approach to the problem of who speaks for an incapable adult involves a procedure, typically set in statute, to identify the substitute decision maker, and only that person will have the right to make decisions.² Invoking rights to solve conflict results in winners and losers.

Andrew's unwillingness to inform his brother and sister of their risk of having inherited Wilson's disease seems difficult because relationships within families are not well described by rights. The typical analysis of this sort of case focuses on the patient's right of confidentiality and the common law limits placed on such a right. In North America, these limits are defined in *Tarasoff v Regents of University of California*.³ According to this legal case, the physician has a duty to breach the patient's right to confidentiality in the event of imminent risk of serious and preventable harm to an identified other. Some people argue that Andrew's right to confidentiality should be breached, given the risks posed by Wilson's disease to his siblings and the fact that treatment may prevent this harm.

I think this is the right answer, but the wrong reasons are given for it. A blind eye is turned to the dissimilarities between cases about genetic information and the *Tarasoff* case. The probability of carrying the gene or genes is often not high—in this case, only 25%—and the risk is typically not to a single person, but to a group of siblings. Furthermore, family members may discover through other means that they have the condition in question such as routine

medical examination or awareness of a family history of the disease from other sources. Finally, although Wilson's disease is treatable, no effective prevention or treatment methods exist for other heritable conditions. We need, therefore, a new moral lens through which to view such cases.

FAMILY ISSUES

The central flaw with the above analysis is that it applies to a family a set of moral rules for strangers. It seems strange to invoke a right of confidentiality within a family. Family members are not strangers to one another; rather, they share an indissoluble bond.¹ Familial relationships are understood productively as ethical duties that family members owe one another.² Siblings owe each other a duty to respect and care. Andrew is obliged to disclose his diagnosis to his brother and sister precisely because they are his siblings. Failing to tell them would breach his duty to care for them. If his current mental state makes him unable to discharge this duty, he must find another, such as his general practitioner, to do so for him. Our analysis leads to the same conclusion as above: the family must be informed of the risk of Wilson's disease. The steps that lead us to this point, however, have nothing to do with rights and everything to do with family obligations.

References

- 1 Freedman B, Weijer C, eds. *Duty and Healing: Foundations of a Jewish Bioethic*. New York, NY: Routledge Press; 1999.
- 2 Freedman B. Respectful service and reverent obedience: a Jewish view on making decisions for incompetent parents. *Hastings Cent Rep* 1996;26:31-37.
- 3 *Tarasoff v Regents of University of California*, 551 P.2d 334 (Cal Sup Ct 1976).

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ANY ANSWERS?

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